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ABSTRACT

This guidebook's aim is to encourage the development of good working relationships between parents and service professionals for the benefit of children or young people with disabilities. It begins with a list of reasons for partnership and a discussion of the needs and strengths of families. It then examines the essence of partnership, which is described as professional accountability to parents and equality between parents and professionals. An age-based approach is used to discuss the needs of children, from preschoolers to adolescents, and the implications of these needs for partnership development. A final chapter discusses overcoming obstacles such as lack of training, psychological and social distance, and reconciling the child's needs with the needs of other family members. Suggestions for successful partnerships are made, guided by the principle that if people are to work together more successfully, they will have to get to know one another as human beings first and only secondly in their role of parents or professionals. (Includes 31 references.) (JDD)

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Guides for Special Education No. 2

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Guides for Special Education No. 2

Working together

Guidelines, for partnership between professionals and parents of children and young people with disabilities

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Unesco, 1986

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PREFACE

This guide is the second in the new series 'Guides for Special Education', published by Unesco.

The guides, which are intended for teachers, parents and community workers, aim at stimulating discussion on basic knowledge, methods and techniques relevant to the education of handicapped persons, and offer practical advice for action in this field.

The first guide 'The Education of Children and Young People who are Mentally Handicapped' deals with ways to encourage learning and gives concrete suggestions on what to teach.

This guide is expected to interest a wider readership, for, in addition to teacher-parent collaboration it deals with the relationships between parents and various other professional groups.

This guide also serves as a supplement to Guide I on 'The Education of Children and Young People who are Mentally Handicapped' and to the forthcoming guide on 'The Education of Deaf Children and Young People'.

The views expressed in this guide are those of the authors and do not necessarily reflect those of Unesco.

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CHAPTER I: INTRODUCTION: A JUSTIFICATION FOR PARTNERSHIP

This guide has been written to encourage the development of good working relationships between parents and professionals for the benefit of the child or young person. It seeks to provide a definition of and a justification for collaboration; it gives examples of ways in which parents and professionals can work together at different stages in promoting the development of children; and it discusses the difficulties and obstacles which stand in the way, and how these might be tackled and overcome.

The growth of better working relationships between professionals and parents of children with disabilities constitutes one of the most important developments in the field of special education and rehabilitation services. But despite encouraging evidence of the benefits of such collaboration to children, as well as to families and to professionals, progress has been slow and uneven. This unevenness is not directly related to the degree to which services are well developed or well resourced. Some of the most interesting examples of parent-professional relationships have come from poorer countries with only limited resources. Countries with advanced and well-established educational systems have often found it difficult to break with traditional practices which create a distance between home and school.

In writing this guide for an international readership, we are conscious of the vast range of cultures, traditions and practices in different parts of the world. Although we are most familiar with the needs of families and professionals in the United Kingdom, we have done our best to learn about practice in other countries. The International League of Societies for Persons with Mental Handicap (ILSMH), from whom this pamphlet has been commissioned by Unesco, contains over 100 member societies in some 70 countries in all five continents of the world. We therefore wrote to all the League's member societies, asking for information about their experience of parent-professional relationships in their own country, whether successful or unsuccessful. We also asked for their suggestions on ways in which better relationships might be achieved. We received many interesting and helpful responses; these are acknowledged in the appendix. Further information is available through the International League of Societies for Persons with Mental Handicap.

Throughout this guide, we will use the term 'professional' to include a wide range of people. They include teachers working with children and young people of all ages, whether attending school or not; health professionals working in peoples' homes as well as in health centres and hospitals; staff concerned with helping

adolescents and young adults to live, learn and work in their local community, as well as social workers and staff of voluntary agencies. We therefore need to think of the goal of partnership as it relates to all those people with whom the child and the family come into some form of working relationship.

This guide seeks to promote good working relationships between parents and professionals as a first step in the building of partnership. We see true partnership as the ultimate goal, and good working relationships and collaboration between parents and professionals as essential stepping stones towards this goal. A commitment to partnership implies a sharing of knowledge, skills and experiences in meeting the individual needs of children as well as the individual needs of families. It assumes that children will learn and develop better if parents and professionals are working together than if either is working in isolation.

REASONS FOR PARTNERSHIP

There are many facts and arguments to support the development of closer working relationships between parents and professionals. We summarize some of the more important considerations below:

1. Growth and learning in children can only be understood in relation to the various environments in which the child is living. These include the family, peers, schools, the local community and the wider society. The study of child development calls for an examination of ways in which the child interacts with, affects and learns from these environmental influences. We can neither study nor teach the child in isolation.

2. Parents and professionals concerned with the development of children with disabilities share a number of basic goals, e.g. teaching the child self-care and social independence, including feeding, dressing and toiletting. They are both concerned with helping the child to learn to communicate and to understand others and finally to adapt to the expectations of the local community.

3. Parents and the extended family are the adults who are normally most accessible to the child. They are therefore the most easily available people to help a child with a disability. Professional expertise - which is more expensive and in many countries less available - is therefore most effective if it is used to help as many parents as possible to help their own children. Some parents can then share their skills with other parents.

4. Parents and professionals each have essential information which needs to be shared among all who are concerned with the child's development. Parents know their own child best, as well as the environments in which the child is growing up. Professionals have developed certain specific strategies and methods to help children to acquire the skills they need. The greater the child's difficulties, the greater is the need for parents and professionals to adopt a reasonably consistent approach to achieve particular goals. Such methods need to be discussed and agreed, so that, at the very least, each is familiar with the approach taken by the other.

5. Knowledge and experience of bringing up non-handicapped children and ordinary parental intuition, while undoubtedly valuable, are not necessarily enough to aid the development of a child with a disability. Nor is it enough to prepare parents for some of the specific difficulties which they may experience in raising children whose development is not proceeding normally.

6. The age of the handicapped child is not always an adequate guide for the parent. Parents may become discouraged by what may appear to be a general lack of progress. They may be puzzled by the child's uneven development - particularly slow in some areas, relatively normal in others. They may be confused about the kinds of demands and expectations which are appropriate for their child, how they can extend the child's range of experience and how they can both protect the child and promote development. It is in areas such as these that the wider experience and knowledge of the professional can be particularly helpful in preventing difficulties and problems which could, unwittingly, add to or complicate the primary impairment. The professional is in turn dependent on the parents' observations, and on the day-to-day adaptation and implementation of the advice which they offer.

7. In a number of countries, parents' rights to be involved in discussion and decision-making concerning their child are now incorporated in law. Such rights include the right to information, access to records, participation in assessment and in the development of plans to meet the child's needs, as well as in regular reviews of progress. Although only a few countries have so far adopted such laws, the principles underlying collaboration between parents and professionals are increasingly accepted as good practice in many countries.

CONCLUSIONS

Despite enormous differences in progress and practice throughout the world, we believe that the needs of children and families have enough in common to justify this attempt to develop certain general principles, as well as more specific guidelines for action. These might form a starting-point for discussion at local level and will need to be adapted to local circumstances.

Most of the examples of partnership between parents and professionals which have come to our attention are reported from special schools. Will it be possible to develop the same kind of partnership with teachers in ordinary schools? This is one of the major challenges for the future.

CHAPTER II: THE NEEDS AND STRENGTHS OF FAMILIES

Families of disabled children vary as much in their behaviours and attitudes as any other families. The fact that they have a disabled child does not make them any more homogeneous as a group than they were before the birth of the child. It is the task of professionals not only to recognize the distinctive and unique characteristics of each family, but also to approach the task of building a working relationship with the family in flexible and individually appropriate ways.

The needs of families will differ in relation to:

- the nature and severity of the child's disability;
- the stresses on the family and their own resources for coping;
- the attitudes of the society they live in towards disability;
- the nature of the services they receive.

However, before discussing families' special needs, and reactions to disability, it is necessary first to stress the essential similarity in many respects between families of disabled children and families of non-disabled children. For example, problems of poverty and poor housing may be more acutely stressful for families than the child's disability. Research on the family life of disabled children in developed countries has concluded that, in general, families meet the day-to-day problems created by the child's disability in ways that are fairly typical of the behaviour of any other family (e.g. Hewett, 1970). Most parents of disabled children have also had other normal children, and therefore have considerable experience not only of child-rearing, but also of helping their children to achieve independence as they grow up. It therefore makes sense, in creating services, to harness the experience and expertise of parents in bringing up their own children, and in knowing the needs and strengths of their disabled children.

To stress the essential individuality and normality of families is not to deny the range and severity of the problems they face. The aim is rather to challenge the assumptions and stereotypes which are so often used by professionals about the underlying social pathologies to be found in the families. What is at stake here is the danger that negative attitudes in professionals will result in a lack of appropriate action in response to families' needs. For example, parents seeking help at an early stage have frequently reported being labelled 'over-anxious' and denied credit for close

observation of their child. With the current emphasis on 'care in the community', families seeking residential care for their disabled member may be investigated for 'guilt' and 'rejection'. On the other hand, if respite care services are available, parents who do not wish to use them may be labelled 'over-protective'. So the behaviour of families may be interpreted as abnormal whatever they do. Such negative stereotyped judgements are a poor basis for collaboration.

Family reactions

Even in countries where many surveys have been done of the needs and feelings of families of disabled children, services may still be set up in ways which reflect the needs and priorities of professionals rather than of families. Still more information is needed as to how the family as a whole may react to a child's disability, and what needs different family members may have.

A wide range of parental reactions have been documented to the discovery of the child's disability. Parents' feelings may seem both protective and rejecting in response to the abnormality. They may feel inadequacy as parents, and fear for the future. They may experience feelings of bereavement and embarrassment (Cunningham and Davis, 1985). Less is known about whether these reactions are also characteristic of other members of the family such as sisters, brothers or grandparents, and how the feelings of one member of the family affect another member, spouse to spouse, parent to child, etc. For example, some fathers may seem to shut themselves off, work long hours, and not talk about their feelings; this will in turn reduce their capacity to support the mother emotionally. Family members' strong and long-lasting feelings need to be accepted by professionals, and seen as a natural reaction. Periods of careful listening are an essential element in practical partnership.

A pressing need for many families is for information. Research suggests that for parents (though perhaps not for siblings) the need to understand the nature of the child's disability more fully is a priority. They also need to know what to expect in the future not only in terms of the child's development but also in relation to whatever community services, aids and grants may be available. Finally, parents need to know what they can do to help the child. The ways in which such information is made available need careful consideration and ingenuity - for example, leaflets with explanatory illustrations, radio programmes, etc.

The task of bringing up a disabled child is a complex and tiring one. Children may be a drain on the family finances, through needing special equipment, replacement of bedding if the child is incontinent, replacement of clothing worn out quickly if the child is crawling, difficulty in travelling, and attendance at hospital appointments. Also family finances may be affected through the mother not having paid work, wanting to stay with the child or not

being able to find someone who will do so while they work. The everyday tasks of child care are greatly increased, as many children need constant supervision in order to keep them occupied and out of danger, and occupied in play. Feeding, toiletting, washing may involve parents' time and attention for much longer than in the case of non-disabled children. Repeatedly having to lift a physically disabled child will be exhausting. Many disabled children have disturbed sleep patterns, which will further drain parents' energy.

So the services which parents may much appreciate are those which provide someone to share the burden of caring - 'babysitting' while the parent goes out for a while, helping during school holidays, befriending the child, etc. In countries which have a choice of services, play groups, toy libraries, transport services and financial aid are all important provisions in supporting parents in caring for and enjoying their child.

Families need information and opportunities for discussion as an essential foundation for helping them to make rational and informed choices about ways in which they can make best use of existing services, or press for services that are not available or are being employed in ways that do not meet their needs. Parental feelings of fear and inadequacy are a natural reaction to disability in a child, but for such reactions to be prolonged may be a direct reflection of lack of appropriate help from professionals.

Coping

Families and family members will also differ in the extent to which they have resources for coping with the stresses and strains resulting from the child's disability:

physical health and emotional stability;

past experience in problem-solving, such as seeking out information and support;

the helpfulness and size of their social network;

financial resources;

their values and beliefs.

Thus, in setting up a working relationship, professionals have to be aware of parents as complex individuals with their own resources and strengths, as well as having areas in which they need support. It may be as important for professionals to enable mothers to look after their own physical health, as to consider the child directly. It may be as important to facilitate parents of disabled children meeting each other for mutual support, as to focus direct services on the disabled child.

Parents' perceptions of society's view of the disabled child are likely to have a strong influence on their feelings about their own capacity to love and care for the child in the family. There have been few cross-cultural studies of public attitudes to disability, and much of what is 'known' is anecdotal. Such surveys as there are demonstrate the dangers of generalization - community attitudes vary not only across societies but also within them, even between adjacent neighbourhoods. It is also the case that community attitudes reflect both positive and negative impulses towards disability (Mittler and Serpell, 1985). It will be an important aspect of partnership with parents, for professionals to help parents to gain positive support from the community, for example, through community leaders, or women's organizations, giving members accurate information about the disabled child and encouraging the child's inclusion in community activities.

Parents' attitudes and beliefs, as a reflection of society's attitudes, may need to be expressed in discussion in order to examine where they may conflict with professionals' assumptions. For example, in order for parents to work with professionals in promoting their child's development, there will need to be acceptance of the idea that intervention can be effective. Some parents of intellectually disabled children may not believe that the child can be helped to progress. A second example is where professionals suggest that parents spend time in teaching their children new skills in regular, structured sessions. Yet it may be culturally unfamiliar, or felt completely inappropriate by parents to spend regular periods in intensive play with their children, let done such activities being difficult to arrange when parents have to work long hard hours. The culture of the society may instead emphasize children's independence from their parents in terms of daily activity. Professionals may then need to consider ways of involving other children in aiding the disabled child to progress, or developing strategies with the parents whereby the time they already spend with the child (e.g. feeding, dressing) is exploited in terms of promoting the child's development of skills towards independence. Models and assumptions about services which are seen as useful in one country will not be appropriate for implementation unrevised in other settings.

Family members

1. Unsupported mothers

So far we have used the term 'parents'. However, many mothers are in fact looking after disabled children on their own, with little help or support from other family members or from the surrounding community. Also many families are headed by only one parent, usually the mother. Unsupported mothers have special problems. Even in the few countries where special financial grants are available to parents of disabled children, these are rarely

adequate to provide help in the day-to-day task of looking after a home and caring for and working with a disabled child. Many mothers have to, or choose to have paid work, just as mothers of non-disabled children do. Professionals need to be fully aware of the pressures on mothers, and not create additional pressures through the programmes they suggest. A range of flexible services for mothers to choose from would be the ideal.

2. Fathers

Contacts with professionals have often excluded fathers in the past. Where fathers are for any reason not available (e.g. work commitments), it may be very difficult for mothers to pass on the information and advice they have received from professionals or other parents. Thus the effect of service provision may be in some ways to divide the child's parents, to make fathers feel incompetent in relating to their disabled child, and to lead to inconsistent handling. In most societies, men take a limited part in the day-to-day tasks of ordinary child-rearing. To what extent should professionals try to expect more of fathers, since special children create extra burdens and may call for special measures? What extra information and opportunities would fathers appreciate and respond to? These are questions which need raising in discussion between parents and professionals, in order to meet parents' needs flexibly.

3. Sisters and brothers

These are perhaps also questions to ask in relation to siblings. It used to be generally assumed that brothers and sisters would inevitably suffer from the presence of a disabled child in the family; indeed, it is with their needs in mind that physicians have often prescribed institutional care outside the family. But there is very little evidence which would support such an over-simplified view. Of course, there are individual families where the siblings have undoubtedly suffered, and some consistent evidence that older sisters may have too much expected of them in terms of helping to care for the disabled child. But in general the picture from a number of studies is not of widespread adverse effects.

On the other hand, we have little information on the ways in which siblings can contribute positively to systematic work in partnership with parents and with professionals. Here again it is important to respect local social and cultural traditions and the wishes of parents and siblings themselves. In many countries, siblings play a large part in caring for small children. On the other hand, many parents do not wish to involve the disabled child's siblings in detailed programmes of stimulation and training or in taking the child with a disability around with them, on the grounds that they should be allowed to get on with their own lives and that the presence of a disabled child imposes adjustment problems enough

on siblings without demanding additional efforts from them. However, much can be gained by sharing feelings, information and work, strengthening family bonds; brothers and sisters too should be helped to choose whether and to what extent to participate.

4. Grandparents

We have almost no research information about the reactions of grandparents (and other extended family members) to disability in a child, and about the role they can play in helping the child and parents. Certainly grandparents do have strong reactions to their grandchildren, and can be a source either of great support or of tension to parents. Research does suggest that even in developed countries in urban areas, contacts with grandparents are frequent in a high proportion of families. Grandparents' role often seems to be one of providing general support: financial help, making special clothes or equipment, being there in a crisis. Professionals can in turn sensitively support this important role, in their attempt to build a broad-based and flexible working relationship with families.

Thus no one approach can ensure success in working with all families of disabled children, because each family is unique. Different family members have different reactions to the child, and different strengths in coping and adjusting. Each family and extended family has different ways of communicating with each other, and in asking for and giving help and support. However, the next chapter suggests some principles on which successful collaborative working relationships between families and professionals may be based.

CHAPTER III: THE ESSENCE OF PARTNERSHIP

We have stated in the introduction that we see partnership as the essential principle on which to base the development of working relationships between professionals and parents of disabled children. In this chapter we attempt to define what we mean by partnership.

The partnership we have in mind implies professional accountability to parents. It also implies equality between parents and professionals. Partnership can take many forms but all must rest on a basic recognition that each side has areas of knowledge and skill to contribute to the joint task of working together for the benefit of the child. As a starting-point, professionals might think of parents as active 'consumers' of services, and not as 'patients' (an essentially passive label).

Partnership implies shared activities and decisions. But there cannot be a prescription for particular joint activities which would represent 'partnership' in action. There will be an infinite range of particular forms of working relationship depending on the context within which the work is undertaken and how the family lives. Working together encompasses a wide range of activities, from exchanging basic information about the child's health, right up to parents being very closely involved in the child's education and contributing to decisions about policy and allocation of resources.

Ultimately services to disabled children are a matter of rights, including parents' rights, and thus of professional duties. It is part of the professionals' responsibility and task to make the relationship work as a partnership and be of benefit to the child. Professionals need to strike a balance between offering to help parents to augment their skills in specialized ways (e.g. learning how to do physical exercises, prepare special diets, train their child towards independent mobility, etc.) while at the same time supporting their strengths and sense of identity as parents. Children have complex needs in growing up. Disabled children need from their parents not only encouragement to try harder and teaching to achieve more, but also their parents' unconditional love and acceptance. This balance can only be achieved by consulting parents about their own needs and preferences.

How can professionals assess the nature of the services they are offering against the guiding principle of partnership? There are several key features embodied in the concept of partnership.

1. Mutual respect

Perhaps the key element in the development and success of partnership is mutual respect of the different qualities and skills which both sides bring to the relationship.

Parents and professionals both have a deep interest and concern for the child, but the parent is more deeply involved. Most parents have a lifelong commitment to the child and their responsibility lasts for 24 hours a day, during holidays and sickness. Their feeling of their own capability and worth as parents may be intimately tied up with their child's development. Their detailed knowledge of the child derives from this day-to-day lifelong love and care.

The professional has, on the whole, a more finite commitment. The focus of a professional's work is usually specialized in some way - concerned with education, health, hearing and language, mobility, vocational training, and so on. Also the professional may choose to change jobs, or work with another group of children.

Nevertheless, the roles of parent and professional in the field of disability are more than usually interactive and complementary. The warm and affectionate care of the parent and the physical help a parent offers will need also to be given by the professional. Parents have knowledge, skills and experience in bringing up their child which they can offer to the professional and to other parents. Similarly, the knowledge and experience which professionals have accumulated in working with disabled children need to be passed on as skills to parents, to enable them to minimize the child's handicap by continuing teaching at home.

Mutual respect does not mean professionals standing back and saying 'parents are the only true experts'. Parents look for active, purposeful help from professionals in bringing up their child, but in a way which is fully integrated with their own patterns and priorities for the child.

2. Sharing - common purpose

Partnership involves a dialogue and an agreement of common purpose. It is perhaps surprising how rarely parents have been asked for their opinions - for instance, about what they feel their child should be learning. Professionals can usefully ask parents actively and directly about their ideas, and about their preferences for collaboration. They need to do so at regular intervals as circumstances, needs and priorities change.

Joint assessment of the child should be a process which operates right from the start. Parents have a wealth of information about their child, even if they do not have a systematic way of

reporting it. They also have a wealth of experience, for example, in interpreting the ambiguous cues which a blind child may give as to whether he or she is listening, or the jerky, misdirected movements of a child with cerebral palsy. They know the child's likes and dislikes. Also they have over time built up a way of interacting with and managing the child which, to a greater or lesser extent, is comfortable for them. All of this information is vital to the professional in making a full assessment of the child. Likewise, the process of assessment is an important and revealing experience for parents. Noting all the things that the child can do may 'open parents' eyes' to a new view of the child, where before they may have been concentrating on what the child cannot do. And it can help bring home realities to parents who have not allowed themselves to see the child's difficulties clearly before.

It is from this basis of asking and listening and working together that parents and professionals can develop a mutual understanding and a common purpose. Parents can then find out why suggested activities may be important for a child, and have an informed basis from which they themselves can make suggestions on how the activities can best be carried out. It is important for professionals to encourage parents to ask 'Why?'.

3. Sharing - making joint decisions

The making of decisions is the area from which parents of children with disabilities are most often left out by professionals. They have been expected to fall in with professionals' opinions and planned programmes, or have been given the opportunity only to agree or disagree with decisions already taken. Professionals may be nervous of involving parents at this level, fearing they might take over. This defensiveness is clearly observed by parents. 'Professionals simply cannot resist taking over', was how one group of parents from France put it to us. But joint decision-making, in the best interests of child, parent and professional, is what is implied by partnership.

Parents in some countries have increasingly asserted their wish to be consulted. In the United States of America, for example, the 1975 Education for All Handicapped Children Act ensured that parents are equal members with professionals of the committee which decides on the individual educational programme for the child. Many home-visiting educational programmes (see next chapter) have parents on their management committee, ensuring that the programme continues to be responsive to parents' differing needs and situations. Parents' organizations as well as organizations of disabled people are crucial members of the joint consultative committees which advise many governments on policy.

At the individual level, professionals need to make joint decisions with parents about teaching programmes. These may be

carried out by one or the other, not necessarily together. But for maximum appropriateness and functional usefulness, teaching goals need to be decided jointly. For example, if a teacher or therapist decides that a child needs to learn to sit in a particular beneficial way, there also needs to be a joint decision with the parent about whether or how often to enforce this when the child is with grandparents, or playing with other children.

It is also important for professionals and parents to decide on a method for continuing communication between them, whether this is through written notes, home visits, parents' group at school, telephone, etc. Regular continuing communication is essential to partnership, and as children progress, or problems are encountered, decisions will continue to need updating.

4. Sharing feelings

Partnership involves sharing, not only of skills and information, but also of feelings. It may be vital for parents who sense rejection of their child and of themselves because of the child's disability to experience a professional really enjoying their child, and showing pleasure in what the child does.

Traditionally, parents and professionals are wary of one another. They come together hindered by preconceived assumptions and ideas. If parents expect teachers to be rather remote, superior figures, it will come as something of a shock if they realize that teachers of disabled children may, like themselves, often be floundering and overwhelmed. Also then parents will be unprepared for teachers who offer them opportunities for day-to-day participation in assessing the child's needs and in implementing collaborative teaching. Professionals, as much as parents, will lack confidence in how to approach the other; professionals rarely have preparation or training in ways of relating to parents.

Professionals can begin to meet parents on a personal level by being open about their own feelings. Sharing their initial reactions to disability and early difficulties and failures may make parents more comfortable in expressing their own doubts and worries. Similarly, professionals and parents can help each other through periods when little progress is being made and it is only too easy to be discouraged. Sharing of feelings, with the knowledge that progress often comes in spurts after a consolidation period, can bring comfort to both.

The sharing of positive feelings may be even more important, feelings of warmth towards the child, and feelings of satisfaction at achievement. Success is very precious when much effort has gone into helping a disabled child take even a small step forward in development.

Such a two-way process of support between parent and professional is of inestimable value to the child, but it is only possible on the basis of a genuine flow of communication and some element of joint undertakings and activities.

5. Flexibility

Flexibility of approach in dealing with individuals is fundamental to partnership. Many recipients of professional services have complained bitterly about the generalizations and judgements of professionals - that a disabled child means a 'disabled' family, and that all parents need help to 'accept' that their child is handicapped. Generalizations and stereotypes need constantly to be questioned; no two parents are alike. If professionals want to establish comfortable and productive relationships with parents, they will need to explore with each family afresh what the situation means to them and how each family member can 'live with' and ameliorate the handicapping condition of one member. It is too easy for professionals to slip into routines. Being flexible takes time, but careful preparation is more likely to avoid wasted efforts in the long run.

Partnership means that parents can be involved with professionals in an active working relationship with frequent communication. But it does not mean that parents should be put under pressure to do so. Parents have a right to opt out of an active relationship with professionals: they may not want to act as a teacher to their child, or they may be prevented from doing so by real practical obstacles such as time, over-work, gross overcrowding, severe social or marital problems or sheer exhaustion. If we are serious about listening to parents, we must allow them to choose not to be involved in detailed collaboration. It may be a temporary stage - feelings and circumstances can change - or it may be how that particular partnership continues.

Many parents still regard professionals as special people with special training in working with disabled children. If, for example, they have waited for years for their child to enter school, they need to believe that the child is passing into the care of highly skilled professionals, and that they can at last take a back seat.

Parents and professionals share similar concerns, yet have different perspectives, priorities and pressures. These similarities and differences pose acute challenges to them when they wish to form closer working relationships. The only predictable thing about disabled children and their parents is their diversity. But the effort is well worth while. A constructive partnership between parent and professional, utilizing the knowledge and skills of both, is the most likely way in which the needs of the disabled child will be fully met.

Birth and the first few days

The foundations for good relationships between parents and professionals need to be laid down from the earliest beginnings - often at birth of the child.

Many parents have spoken and written bitterly about the way they were treated by professionals at the time of the birth of their baby. Parents may not be told anything at all, or may be falsely reassured that all is well when the baby is known to have a disability. The news is often broken brusquely and insensitively, sometimes without privacy or a chance to ask questions. Sometimes, information given is misleading or out of date. Above all, parents are not offered any support or assistance, and no suggestions are made about ways in which they can help the baby to learn and to develop.

As a result of many surveys in which parents have been asked to reflect on their experience and to make suggestions for better practice, a number of writers have drawn up general notes of guidance for the use of staff who may be involved in providing the first contacts for a mother who has just given birth to a child with a disability (see Cunningham and Davis, 1985 and Brynelsen, 1984 for recent examples).

Common to all the suggestions is the recommendation that written guidelines should be available in every local area on procedures to be considered in the event of the birth of a baby who has or is strongly suspected of having a disability. These guidelines should be known to all staff working on maternity units and to midwives attending home births. Such guidelines are obviously not intended to be mechanically applied in every case but they do at least provide a basis for discussion at local level:

1. Whenever possible, the person to inform the parents should be an experienced physician familiar with babies with disabilities, fully aware of recent developments in providing help for such children and their families not only in early childhood but also in the school years and into adulthood.

2. Inform parents early, and certainly before mother and baby leave hospital.

3. Talk to both parents together: it is generally unwise to tell only the father and ask him to tell his wife.

4. talk to the parents initially in complete privacy, without students or other staff. At the second meeting, it is useful to involve one more person - e.g. a social worker, public health nurse or fellow parent who will be able to continue supporting the family.

5. Talk to parents in presence of baby, and handle the baby in the same way as any other newborn baby, conveying by language and manner that the child is a child first and foremost, and only secondly a child with a disability.

6. Provide opportunities for parents to see the physician on more than one occasion, so as to allow them time to formulate questions after the shock of the initial interview. If the physician does not know the answers to the questions asked by parents, this should be admitted openly, and steps taken to find the answer if at all possible.

7. Provide parents with a short leaflet with basic information about the condition, and which indicates possible sources of help and support at local level.

8. Inform parents of name of appropriate voluntary organization or parent-to-parent support groups and ask parents if they would like to be visited by a member of such a group.

Guidelines such as these seem to assume that children are born in maternity units and that specialist help is available throughout pregnancy and during and after childbirth. Although this is the case in many countries, it is obviously not so in many parts of the world. Even so, the general principles behind guidelines such as these might be adapted to suit different settings and conditions.

What happens in any community when a mother gives birth to a baby that is quickly perceived as disabled or different? If she herself as well as those around her immediately perceive that the baby has a defect of some kind, how will she and the baby be treated - by those who have helped to deliver the child, by the immediate family, by neighbours and friends? Will the community support her? Will they give her additional help? Such evidence as we have from studies of cultures around the world suggests that generalizations about attitudes to babies with a disability are dangerous. There is great variation from village to village within a relatively small area, even though two villages may share the same cultural or religious traditions.

The earliest months

However sympathetically and positively the parents have been treated in the days following the birth of a baby with a disability, it is when they leave hospital and return home that support and help are essential. But families differ greatly in their response to help that is offered, and it is therefore important to discuss with parents the kind of support that would meet their needs, while still recognizing that parents' views and needs change with changing circumstances.

For example, some parents are glad to welcome another parent with similar experience. For others, the arrival of a parent who has an older child forces them to think about the future when they do not yet feel ready to do so. Similarly, some parents are soon eager to do anything they can to follow the advice of experienced professionals while others need time to 'find their feet'. Again, parents are not always sure about ways in which professionals can help: they may think of them only as specialists in their own field and not think it appropriate to discuss their worries about the reactions of members of their family to the fact that their baby has a disability. Even within a family, it is natural for two parents to feel differently about such a situation.

In many cases, disabilities will only be detected at a later stage. Parents may have suspected that something was wrong over a considerable period. Confirmation will be distressing but may also be something of a relief. For other parents, finding out that their apparently normal child has a disability will be a terrible shock, and perhaps harder to come to terms with just because of the initial period of thinking that their child had no problems.

Parents have often said that their main need in the earliest months is simply to have a friend who is a source of support and comfort, someone to talk to freely - not just about the child but about anything. And yet, parents of babies with a disability are often isolated - not necessarily because the baby is 'rejected' but because their friends and relatives are unsure how to behave and how to react.

As one parent said:

> 'Most of my relatives do not talk about Beckie with me ... but leaving the topic unmentioned is to treat a major segment of my mental and emotional life as unmentionable' (Morton, 1978).

Home- and community-based services

The movement to ensure that basic community resources are made available to all members of the community, including those with disabilities, has been actively promoted by international

organizations such as the World Health Organization, UNICEF and Unesco. In the field of primary health care, local village workers in many countries are being given short courses of 'on-the-spot' training in the basics of health care, sanitation, nutrition, childbirth and child care. To this is now being added some of the most essential elements of helping families and communities accept and assist children with disabilities. Detailed training manuals are now available from WHO in Geneva and from all regional offices of WHO to assist village health care workers to help parents to teach their children to learn to become more independent in feeding, dressing, toiletting and in learning to communicate (Training the Disabled in the Community: A Manual on Community-Based Rehabilitation for Developing Countries, WHO, 1983). These manuals can be used from the earliest months of life. They are written in simple language and liberally illustrated with line drawings providing examples of how particular skills can be taught. Separate manuals are available for people with difficulties in learning, movement, sight, hearing and speaking, those who have fits and those with 'strange behaviour'.

Many families with a young child with a disability are now being helped to meet their child's needs in their own home. However, such a policy demands that parents are given full community support and given all possible sources of help to enable them to do so. Such help will vary from community to community, depending not only on resources but also on ways in which families with any other child might be helped. In some countries, children can attend day centres, creches or kindergartens for part or the whole of the day, sometimes where disabled and non-disabled children may mix freely. These may be provided from public funds or they may be run by voluntary agencies. Similarly, some countries have nursery schools or classes run by the education authorities and staffed by experienced nursery teachers and nursery nurses.

Some countries do not have day services for any of their children, whether disabled or not. Even if they do, it may be difficult to secure admission to such services for children with disabilities. there is general agreement, however, that young children would generally benefit from attending pre-school day services but that mere placement of such children in integrated facilities is only the starting-point. Being in the company of normally developing children provides essential learning experiences for all children, as well as for staff. But it is also important to find the means of meeting the special needs of children which arise from their disabilities.

In situations where the child is attending a pre-school facility alongside normally developing children, the following questions can usefully be asked in relation to parental collaboration in meeting the child's needs:

1. What opportunities have there been for parents to visit the pre-school facility, to talk to the staff about their child's ordinary and special needs, ways of helping the child settle in and gain the maximum benefit from attending?

2. Do the day centre staff have opportunities to visit the family at home in order to see the child in the home setting and get to know the family on a social basis?

3. Are the centre staff informed about the results of any specialist educational or developmental assessment that has taken place, as well as of any specific or general recommendations for teaching and activities that have arisen from such assessments? How fully have the parents contributed to such assessments and recommendations?

4. What support is available both to centre staff and to the family in dealing with problems presented by the child during this period?

5. Are parents able to visit the centre freely to take part in activities with other children or with their own child?

6. If the child has been taught at home by the parents, either on their own initiative or with the support of a home visiting programme, what steps have been taken to inform day centre staff of progress and problems in following such teaching? Are parents involved in any modifications to the programme which may be necessary as the child moves into a day centre? How regularly would such a programme be reviewed by centre staff?

What about children who do not attend any kind of pre-school service, whether ordinary or special? In some countries, home visiting services are being developed to assist and support such families. These take many different forms. Some are relatively informal, unstructured forms of visiting. For example, parents have themselves developed support groups in many places, whose members visit one another in their own homes to share experiences and ideas and to provide mutual support on a social basis. In other cases, regular visits are made by a teacher, public health nurse, health visitor or social worker. They too provide general support but may also advise on difficulties which arise, as well as inform parents about local services. They may also accompany parents on visits to assessment centres and to possible services which are being considered for the child.

Increasingly, the aim of home visits is to help the parents to further the child's development. The best known formal programme of this kind is the Portage programme (Dessent, 1984). Originally

developed in a rural community in Wisconsin, United States for all pre-school children with delayed development, the programme has now been adapted and translated for use in many parts of the world, including Latin America, India and the Caribbean. In essence, programmes such as Portage involve a regular visit, every one or two weeks, by a home visitor who works with the parent to arrive at a simple assessment of the skills attained by the child in key areas of development - e.g. physical, self-help, movement, play, socialization and language and communication. This assessment is then used as a basis for discussing with the parent the next stage of development that the child might be helped to reach, the activities that would help the child to reach the target and the methods that might be used to this end. The home visitor might demonstrate teaching methods and activities to be adopted but it is essentially the parent who acts as the teacher after the home visitor has left. In this way, the programme supports rather than supplants the parents.

Programmes such as Portage have the advantage of being home-based, involving the parents in assisting their child's development, giving them a major say in decision-making concerning the selection of teaching targets. On the other hand, it is important not to put undue pressure on parents to participate in programmes of this nature. As Sandow (1984) puts it, 'There is more to family life than training children', and success or failure as a parent should not be equated with the extent of a child's progress in meeting teaching targets, however important or relevant they may be.

Parents are now being given more choice in deciding the way in which they are going to work with their child. This is consistent with the philosophy of regarding the parents as consumers, respecting the individuality and uniqueness of each family, and the distinctive life-styles and teaching-styles of each member of the family, including the child with a disability.

If parents are to make such choices, they will need to be in possession of all the necessary information to enable them to choose in an informed way. Some parents may wish to take a full part in contributing to the assessment of their child, as well as in selection of teaching targets. But they may prefer to reach these targets in their own way, fitting in with the child's moods and interests, rather than follow a prescribed method of teaching or committing themselves to reach such targets by a set date that fits in with the home visitor's next visit.

It is precisely because the personal and social needs of the family are so important, that it is important to do everything possible to allow them to lead as natural a life as possible, despite the difficulties presented by the child. For this reason, social, personal and financial help for the family are at least as important as direct educational help for the child.

Such sources of help can include:

1. Arrangements which will allow the family to meet friends and leave their house during their leisure time. This may involve someone coming in to look after the child or the child going to another person's home. It can also involve short periods of respite care with other families. This helps not only the family but can also provide the child with invaluable experiences of living away from home for short periods.

2. Countries with a well-developed social security system now generally provide some degree of financial help to parents looking after a child with a disability. Even where this is not available, assistance with transport can be invaluable.

3. Toy libraries have provided a source of support for many families, as well as stimulation for the child. Parents can borrow toys and play materials which suit the stage of development reached by their child; often, they can seek advice from a teacher or volunteer familiar with the play needs of young children. Toy libraries provide an informal setting in which parents can meet and exchange ideas and experiences concerning their children. Many are available to parents of all children, whether they have a disability or not.

4. Many parents find it helpful to become members of a parent to parent support group. Parents meet regularly in one anothers' houses, not only to talk about their children or the problems they present, but as a means of mutual support and building up self-confidence through being able to help others. Sometimes, such groups provide individual support to a new parent.

CHAPTER V: WORK WITH PARENTS DURING SCHOOL YEARS

INTRODUCTION

The organization and structure of educational provision varies greatly both between and even within countries. In some, education is provided entirely by the State or from public funds; in others, schools for children with disabilities are set up by parent groups themselves, or by private or voluntary organizations. The access that parents have to their child's school, to information about their child's progress and problems and the nature and degree of influence that parents exercise will also vary - from a bare minimum to one of maximum control stemming from the status of parents as employers of teachers.

Educational provision for children with disabilities is in a state of change and uncertainty in most countries of the world. In many parts of Europe, North America and Australasia, the practice of segregated education is being questioned, and attempts are being made to meet special needs in ordinary schools. This can take a variety of forms. For example, special classes for children with disabilities can be set up in the ordinary school; alternatively, children are placed directly into an ordinary class but attempts are made to ensure that both the child and the teacher are given a high level of professional support from specialist teachers. Sometimes, children spend part of the day in the special school and part in an ordinary school (see Hegarty, Pocklington and Lucas (1981) and OECD (1981) for summaries of the range of models currently found in developed countries).

Progress towards the integration of children with disabilities is very uneven. Children with physical and sensory disabilities are more easily accepted into ordinary schools, whereas those with marked difficulties of learning or behaviour are still frequently excluded from or not accepted by ordinary schools. Nevertheless, there can be no doubt of the increasing commitment to integration (mainstreaming) by educationalists and parents, although the obstacles to achieving high quality education are considerable.

In many developing countries, only a small minority of children with disabilities attend any form of school. Where they do, priority is generally given to children with sensory and physical disabilities; those with learning and intellectual disabilities tend to be lower on the priority list. In general, parent and voluntary organizations are the ones who struggle to secure an education for such children. Sometimes, individual parents succeed in finding a place for their child in a school; in addition, small groups of parents

work together and establish their own school, either teaching the children themselves, perhaps in their own homes or a borrowed or rented room or hall, or hiring a teacher to do so. Bangladesh provides a good example of the growth of a strong parents' society from modest beginnings.

Sometimes, the parents hope to persuade the education authorities to provide schooling by demonstrating that the children are capable of learning. In other cases, the parents prefer to work for financial support from the authorities to enable them to continue to run their own school.

Unesco and other bodies have published examples of a range of approaches to the education of children with disabilities, based on the experience of many different countries (see bibliography for examples of publications and tape slide presentations). But we know rather little about relationships between teachers and parents in countries outside Europe and North America, though some of the replies we have received to our inquiries were encouraging.

It is now regarded as good professional practice to develop an individualized educational plan for each child. The Education of All Handicapped Children Act (1975) in the United States and the 1981 Education Acts in Britain are two examples of national legislation which specifically provides rights for parents to participate fully in the process of assessment and decision-making.

Although there is now a much greater awareness of the importance of parents and teachers working together, this may be harder to implement immediately in ordinary schools, particularly since there may be only a small number of children with disabilities integrated in any one school. Ordinary schools do not generally work in such close partnership with parents, particularly where older children are concerned.

The Italian experience suggests that in may be possible for them to do so. In Italy, the integration of children with disabilities has been mandated by legislation closing special schools, though progress has been more extensive in the northern cities. In many schools, parents are invited into ordinary classrooms as ancillaries to assist not only with their child's physical needs but also, under the guidance of the class teacher, with the academic programme (OECD, 1981). Similar developments are now beginning in Spain; schools which undertake to accept two children with disabilities in each class will be able to reduce class sizes and receive additional support from peripatetic support teams.

Whatever the situation, it seems to us that certain principles are common to the needs of children, parents and teachers during the school years. These principles give rise to a number of specific suggestions for day-to-day practice.

1. There should be opportunities for parents and teachers to discuss their aims and priorities for the child, both in the long term and in the short term

Many misunderstandings and tensions could be avoided or at least minimized if the framework for such discussions existed. It is important that each party should be genuinely interested to hear the other's point of view.

Comments we have received from different parts of the world emphasize that the difficulties which parents and teachers experience in working together arise from different attitudes and assumptions held on both sides concerning the needs of children and the aims of schooling. We suggest that these perceptions should be explored and discussed from the time that the child first enters school, so that parents and teachers can begin to understand one another from the outset. The structure for such discussions will obviously vary - e.g. meetings in school, visits by teachers to parents' homes, meetings in a 'half-way house'. In Kenya, some teachers have been allocated motorbikes to visit families who live some distance from the nearest school.

2. In order to plan the most appropriate curriculum, teaching objectives and methods, teachers should try to learn about the child's home environment in general, and as it relates to the child's learning in particular

This includes such factors as:

(a) Who are the significant adults in the child's home?

(b) What opportunities does the child have to play and interact with other children?

(c) What facilities are available for the child to use at home?

(d) What opportunities are there for the child's learning at school to be extended to the home?

3. There should be joint assessment of the child's skills, abilities and needs.

When a child enters school, there are many areas of functioning that staff will want to observe and record as a starting-point for their teaching programme for the child. These will include mobility, fine and gross motor skills, language and communication, self-help and independence skills, moods, social relationships and friendships. Parents have valuable information to give in all these areas, especially as the child may behave somewhat differently at home and at school.

These differences can be a useful starting-point for further discussion between parents and teachers. They can provide a basis for parents and professionals learning to appreciate each others' areas of expert knowledge, as well as their different perspectives, aims and attitudes. They can also lay firm foundations for the discussion of the aims, objectives and methods to be adopted and shared in teaching the child.

There are now a number of developmental checklists that can be used for joint discussion, assessment and decision-making. Parents and teachers can choose whether to complete these independently or jointly, and at what point they wish to compare their assessments of the child's abilities and difficulties (see Jeffree (1986) for a brief summary). Teachers have also developed simple methods of observation and recording which can be shared with parents.

4. Successful collaboration between parents and teachers depends on the extent to which information is shared during the period that the child attends school

School records provide the means by which professionals can express their accountability to parents and to those who are responsible for the work of the school. But how many parents know what information is recorded by professionals? How many contribute to regular reviews of progress undertaken by the school at the end of each term or each year? Are they able to read or hear the content of all records and reports written by school staff or by outside professionals?

It is essential for parents to have opportunities to know the full content of all information concerning their child's assessment, the progress made by the child in reaching agreed objectives and ways in which teachers have planned to help him or her to do so. They need to be able to add their own observations and comments, based on their knowledge of the child's development and behaviour at home. School records should be designed in such a way as to encourage and facilitate parents' comments.

Opportunities for parents to make their own comments can be arranged in a variety of ways. Face-to-face discussions can take place in school so that the parents can meet all the staff who know the child. Alternatively, a teacher can visit the family at home and meet other members of the family. Ideally, discussions in both settings should take place.

In addition, and where literacy is not a problem, home-school notebooks can travel between home and school. Teachers can write (or draw pictures) to inform parents about the child's activities, diet, progress in independence skills such as self-care and toiletting. The parents in their turn can comment on these, and add information about the child's activities at home during the evenings and at week-ends and holidays.

Home-school notebooks can also be used as the basis for a joint teaching programme in which information is sought and shared on progress, priorities, use of aids and appliances, health problems, as well as on new skills that have been learned or used. In some countries where school transport is provided, the bus driver and helper can be a useful intermediary, passing information between teachers and families. In other cases, older schoolchildren are often shown how to teach younger children. This principle might be adapted to brothers and sisters providing a link between what is done at school and at home. Here again, family circumstances will need to be taken into account.

5. Explaining educational goals and methods to parents

Collaboration in education depends on teachers informing and explaining educational goals and methods to parents in clear and simple language. Although we have emphasized the importance of professionals seeking information and suggestions from parents, it is equally important that parents should be helped to understand what teachers are trying to do in schools. Many misunderstandings which arise from parents' lack of information about recent developments in the content and method of teaching could be avoided. If parents are given such information and shown how the teaching is done, they are more likely to support what teachers are doing. In this way, parents and teachers are again learning from one another and hence strengthening the bonds between them.

6. Sharing successes

One of the most valuable ways of developing collaboration comes from parents and professionals informing one another about and sharing the child's achievements. In the past, information and contact have tended to focus on problems and difficulties in helping the child to make progress. But when achievements are infrequent and only made with great effort, it is all the more important that everyone involved should be able to celebrate each step of progress,

however small. Teachers should always inform parents whenever a step forward has been taken by the child. Where it is practicable, they can invite parents into school to see the child at various stages of a teaching programme. By this means, the parent feels involved in sharing success, and may be encouraged to continue with the programme at home. This is a good way to build up parents' confidence, of helping them to overcome anxieties that they may feel about teaching their child at home and overcoming practical difficulties which they may experience. Sharing the child's achievements helps all those who are involved to appreciate that their efforts are recognized, valued and worth while.

Of course, difficulties and problems will also need to be shared. This will be easier in a context where previous contacts have not focused just on 'bad news' but have given equal time to the communication of shared achievements. If this is done at an early stage, parents have the opportunity to share useful information which may help to overcome the problem.

7. Asking the parents

Asking parents is the starting-point for professionals' work with parents. Teachers need to learn how best to enlist the expert knowledge that parents have about their child since birth, their knowledge about the family's distinctive situation and life-style, the resources of the neighbourhood in which they live, the opportunities it presents for their child and the support that can be expected from neighbours and from the local community. No two families can be approached in the same way, and teachers will have to make an informed judgement about the most appropriate way in which these issues can be discussed with parents. It will have to be done with sensitivity and tact, explaining their wish to make the teaching programme for the child as relevant as possible to the environment of the child's home and immediate neighbourhood. At the same time, parents must have the right not to share such information if they do not wish to do so.

It is particularly important for teachers to ask parents' views and preferences on the central question of how teachers and parents can best work together.

For example, how would parents like to be given information:

Through visits or meetings in schools, or both?

Verbally or in writing, or both?

How often should meetings take place?

How do parents feel about carrying on particular teaching programmes at home?

Other examples could be given, depending on local possibilities and circumstances, type of school or distance from home. We received reports from Bangladesh as well as from England, of parents being asked to complete a simple questionnaire to state their choices.

'Your choice is our choice', was how Bangladeshi teachers put it. It is valuable to ask parents, too, about their curricular priorities and possibly about short-term goals - e.g. in the area of self-help skills. It can make all the difference if the goals chosen are the most significant for the family.

We emphasize the importance of asking parents because in many Western countries teachers are more experienced in telling and instructing parents than in seeking information from them. But collaboration depends on parents feeling that their expert knowledge is sought and valued.

8. Providing opportunities for parents and professionals to choose how to work together

There are many ways in which parents and professionals can work together. A wider range of possibilities offers greater choice for parents and professionals and therefore increases the chance of joint enterprises. These include:

(a) 'Fun' social events: parents have often commented that what matters most in their contacts with professionals is how they relate to one another as people. As one of our respondents put it, 'what we are looking for is not friendly experts but expert friends'. Of course, it is not possible to befriend every parent and member of the family but the fundamental importance of finding common ground where parents and professionals can meet on equal terms cannot be overestimated.

(b) Performances and exhibitions of children's work are traditional attractions for many (though not all) parents. It is helpful if this is combined with time for parents to meet staff informally, either during or after the event. Photographs, videos or cine films of the children at work and play are also a powerful attraction to parents who want to see their child on film and who are happy for others to do so also.

(c) Parents can also be invited to contribute to the school's programme as helpers - not necessarily with their own child. This is particularly useful when extra helpers are needed in an integrated class where there may be one or more children with disabilities who need extra help. Parents may be able and willing to help by listening to

children read or reading with them; in art and craft lessons, in telling stories or helping with swimming or sport activities.

(d) Parent workshops have been held in some schools. These provide a forum in which parents and teachers meet regularly over a period of weeks to share ideas and methods in working with a particular group of children. Such groups may meet during the day or in the evening; they provide opportunities for fathers or other members of the family to attend and discuss ways in which parents and family members can work together to help the child achieve particular goals. For example, workshops have been held for parents whose children are just entering or leaving the school, or for parents of children with similar needs and difficulties. Professionals can also encourage parents' self-help groups at local level.

9. Sharing activities

Collaboration includes shared undertakings, activities and decision-making. Some school staff ask parents for their suggestions and involvement in planning activities for students, for staff and for staff-parent groups. These may include outings, drama productions, fund-raising and leisure activities and other ways of broadening students' experience.

10. Time and physical arrangements for working with parents

Parents are often 'put off' by feeling that they are intruders in the school, and that they are out of place and taking up the valuable time of busy professionals. Many parents who feel at a disadvantage in coming into school may recall their own school experiences. Time and thought therefore needs to be given to making sure that they feel welcome and comfortable in the school.

11. Respecting individual choice

Professionals should not expect that parents will automatically follow their suggestions. Families have many responsibilities and should be free to decide on their own priorities.

12. Participation in training and policy-making

Collaboration in its fullest sense includes planning for future development, formulating policy and putting that policy into practice.

In some countries, this kind of collaboration is possible because the structure for it has been created. For example, in Bangladesh teachers and parents jointly learn about teaching methods

and nearly a quarter of the teachers are also parents. In Britain, since 1980, parents must be included on governing bodies of schools and have a statutory responsibility for ensuring that the special needs of all pupils are met within the school, whether that school is a special or an ordinary school. They therefore discuss the policy of the school, its organization and curriculum and participate in the selection of teachers. In many countries, including Canada and the Netherlands, parents have set up and financed the schools and can therefore expect to exercise a considerable influence on school planning and policy in jointly lobbying for and seeking necessary resources.

Where these structures do not exist, the responsibility of professionals to seek out parents' views, suggestions and participation is all the more important.

This can be done by professionals:

visiting;

offering consultation sessions with parents;

acting as advocates for the family-inviting parents to participate at whatever level and in whatever way is possible and agreed.

The training of all professionals should therefore include not only the skills necessary to teaching students with disabilities but also those needed in order to communicate and work with families on a basis of equality and partnership.

All events and undertakings at any level which include considering the needs of children and young adults with disabilities should invite a contribution from parents. Many countries now invite parents and young people with disabilities themselves to participate in conferences, working parties, planning groups, advocacy and advisory groups which are working to develop and improve services for people with disabilities.

CHAPTER VI: MEETING THE NEEDS OF ADOLESCENTS AND YOUNG PEOPLE

INTRODUCTION: CHANGING ROLES AND EXPECTATIONS

If parents and teachers have built up a good working collaboration during the school years, firm foundations will have been laid for the consolidation and further development of these relationships during the difficult years to come. But the nature of the collaboration will need to change on both sides.

First, the collaboration no longer centres on a child but on an adult with the right to independence and autonomy in exercising choice and making decisions.

Second, because adults have a right to privacy, it may not be appropriate for parents and professionals to be discussing an adult without their full presence and participation.

Communities differ greatly in the ages at which children are expected to assume adult roles and responsibilities. In many developing countries, children below the age of 10 are given important responsibilities - for example in carrying out certain household tasks, in looking after animals or in helping in the fields or looking after younger brothers and sisters. Because families live and work together for longer periods, the notion of adult independence and autonomy which is characteristic of much of European and North American society is replaced in other cultures by communal living and group interdependence.

Such information as we have suggests that very few adults with disabilities receive rehabilitation and educational services in developing countries at the present time (Mittler and Serpell, 1985). Their families do what they can to provide a home and occupation and to integrate them into the local community. But few parents will have anything but the most fleeting contact with professionals. The majority are left to fend for themselves unsupported by public bodies. In this situation, voluntary organizations can help parents to support one another. They can also try to set up facilities or persuade public bodies to do so - e.g. vocational training or rehabilitation services or short-term respite care.

In countries where services of some kind continue to be available to young people after leaving school, there is a possibility of disagreement and conflict between parents, professionals and the young people themselves. What happens, for example, if the young person and the professionals who work with her agree that she is now ready to take a step forward in her independence but the parents

feel equally strongly that she is not? It may be a comparatively small step - going to the local shops, visiting a friend alone, going to a social event, the common disagreements about clothes, coming home late and choice of friends. But the disagreement may be about bigger questions: about readiness to work, to live with friends or even independently, embarking on a sexual relationship or getting married.

At the centre of this debate, and often not included in the discussion, is the young person with a disability. What if she has a point of view that differs both from that of the family and of the professionals? How can she resist the charge that she is being 'unrealistic'? What chance does she have of being heard and respected?

LEAVING SCHOOL

Young people with disabilities have complained that schools were so concerned with providing 'as normal an education as possible', whether in special or ordinary schools, that they failed to prepare them for the demands and difficulties of life after school (e.g. Anderson and Clarke, 1982). How many schools provide opportunities for young people to discuss their disability and its implications for their future life? How often can students discuss their fears and anxieties about the future, about their ability to find and keep a job, their chances of forming a stable relationship with a sexual partner, the physical, as well as the social and psychological aspects of sexuality; their concerns about the long-term future when their parents can no longer provide a home for them? How often are students taught the techniques of assertiveness and social skills training, ways of dealing with people who appear to discriminate against them and who deprive them of their rights or access to society's resources and institutions?

The curriculum available to young people leaving schools is clearly of equal concern to families, professionals and the young people themselves in terms of how well it meets everyday needs. Partnership between all three parties is therefore vital and needs to be put into action well before the young person leaves school. What forms can such a partnership take?

Some of the suggestions listed below reinterpret in the light of the needs of adolescents and young adults and their families principles and practices summarized in the previous chapter concerned with children of school-age. Clearly, the chances of a successful partnership depend on the strength of the foundations laid at earlier stages in the development of children of school-age.

1. Parents and the young people themselves should be fully involved in the process of assessment and decision-making in preparation for leaving school

Where a school already has good working relationships between parents and teachers, joint assessment should not present a major obstacle. On the other hand, both parties will now, perhaps for the first time, need to consult the young person, listen to what they have to say and discuss issues and disagreements with them in an adult manner. This may not be easy when parents and professionals may have been making decisions 'over the child's head' for many years. Ideally, parents and teachers will have been finding ways of consulting the child and providing opportunities for choice and decision-making wherever possible from an early age - e.g. in the choice of what to wear, what to eat, choice between two games or two activities. Of course, there are many circumstances where the possibility of choice for any member of the family are limited or non-existent. But at least the person with a disability should have the same opportunities to express choice and make decisions as any other member of the family. These are the foundations for expressing personal needs at a later age and in more fundamental aspects of living.

Much of what needs to be taught will form common ground between parents, teachers and the young person. Somehow, a balance needs to be struck between ensuring that young people leave schools both with appropriate academic skills as well as with the skills which they will need for adapting to the demands of independent living as a young adult. This balance needs to be found afresh for each person and therefore re-negotiated each time between all those immediately concerned. Failing to involve the family in depth and detail at this stage is to do a serious disservice to the young person and to the family as a whole.

It is important, therefore, for schools to make the whole process of assessment and decision-making accessible to parents and to the young people concerned. Assessment must be 'demystified', less technical and more related to the practical needs of the situation. For this reason, schools are increasingly using functional checklists of skills and behaviours relevant to the demands of everyday living. Examples of such a checklist includes Pathways to Independence (Jeffree and Cheseldine, 1982) and the somewhat more detailed Social Assessment Coping Scale (SACS) (Whelan and Speake, 1979). These scales lend themselves to joint assessment by parents and teachers and, indeed, by the young person being assessed. Although some schools do make a practice of asking the young person to assess themselves, very little published information is available on this practice. Not only is it instructive to compare the youngster's self-assessment with that carried out by parents and professionals, but discrepancies can often form an excellent starting-point for discussing priorities. Furthermore, some scales

such as the SACS make it possible to indicate that a student has not had an opportunity to learn or practise the skill. Here again, the student may be more ready to remind teachers and parents of these missing opportunities. This information should then directly suggest appropriate areas for the educational curriculum of school-leavers. Particularly at this point of change in their life, learning to live and learn in the local community will be at least as important as academic skills.

Thus, it is not only the parents but the young student who is all too often the 'missing person' in the assessment process - missing in the sense of taking an active part in his or her own assessment, rather than just being passively assessed by 'experts'.

2. Teachers should visit families in their own homes

It is generally useful if teachers ask parents whether they would welcome a home visit at this time. This would provide opportunities for discussing their more general concerns about the long-term future. If any of these concerns are outside the teacher's competence, the teacher will wish to suggest where and how the parents can best be helped. In some countries, questions of social security and housing entitlement are so complex that only a specialist social worker can answer them; in other cases, referral to a medical specialist may be advisable.

In the case of many young people, however, parents will be interested in ways in which they can continue to help their son or daughter to learn the skills which they need. Teachers can make valuable suggestions on this score, recommend books and manuals where appropriate or make direct suggestions themselves. Many schools continue to offer informal support to parents for some time after the young person has left school.

3. Parents should participate fully in decision-making and case conferences

A number of agencies are involved in the process of assessment and decision-making concerning the needs of a young person and ways in which they might be met at local level. Since the initiative in assessment often lies with the school, it may be convenient to hold a case conference with all those with an interest in the young person. The parents and the young person concerned are clearly key members of such a case conference and should participate fully from the start.

Some parents have complained that they have been kept waiting while the professionals discuss and make decisions and are then only invited in for the purpose of being informed of the decision and asked for a 'token comment'. This is less likely if teachers and parents have a long history of working together and have learned to

respect and trust one another. On the other hand, other professionals may insist on meeting in private so that they can discuss concerns about the family which they would not wish to voice openly. This may be understandable but is a poor basis for working together and impoverishes the meeting.

4. Parents should have opportunities to talk privately to all the professionals involved in decision-making

Although the parents and teacher may know each other well, the parents may well want to have a discussion with one of the other key professionals involved. Their judgements may be crucial to the future of the young person and therefore of the family and it is only natural that parents should want to meet and question them.

However, this is not easy to arrange. A case conference provides few opportunities for subsequent discussion with more than one or two members. It may be preferable to invite the parents to be present if one of the visiting professionals is meeting or working with the young person - this may be a psychologist, social worker or doctor or a staff member from one of the services for school-leavers. It may also be productive for one of these workers to visit the family at home - particularly if there is a social worker involved who has not yet done so. In many countries, it will be social work or social welfare agencies that have the major responsibility for service provision and for supporting the family. Liaison between them and teachers is essential.

5. Reports should be written for parents and for the young person involved

Parents often find it helpful to have a report written for them and in language that they can understand. This applies not only to the discussions and conclusions of case conferences but also to summaries of assessments, whether objective or subjective. For example, parents have been given their own copies of some of the functional assessment checklists mentioned earlier (e.g. Pathways to Independence). Where suggestions have been made for activities for the parents to carry out, it is helpful for these to be summarized on paper, so that misunderstandings can be avoided. It is useful for parents to be invited to add their comments to such assessments, if they have not already had an opportunity of doing so.

How often are reports written for the young person at the centre of the process of assessment? Many would not only be able to understand such reports, particularly if they were written in clear and direct language, but would also find it helpful to have a summary of the assessment and of the decisions taken.

Even in countries with highly developed services, there is often a stark contrast between the quality and quantity of services

provided for children and those available once they leave full-time education. This is partly because of lack of resources but is often the result of an absence of communication and co-operation across administrative boundaries. A full report at the school-leaving stage which identifies specific needs and ways in which these might be met provides one way in which service providers can express a commitment to providing continuity of services. Such a document also provides a means of expressing accountability both to the young person and the family.

Ideally, such a document should constitute a passport to services, listing the young person's needs, the decisions taken about how those needs are to be met and the steps to be taken to review progress. Needs do not change just because the young person becomes the responsibility of another agency. Someone who was thought to need regular sessions of speech therapy or physiotherapy or who received regular examinations by a school doctor or nurse does not suddenly cease to have these needs on reaching their 16th or 29th birthday. Such a document enables service providers and other professionals to express accountability to the client. At the very least, a document clearly specifying the needs of the person with a disability will help parents in their search for appropriate services in the post-school years.

6. Parents should be offered opportunities to work closely with teachers to help their son or daughter achieve relevant skills

A number of schools have worked very closely with parents in an effort to establish an intensive programme of joint teaching on priority areas selected by parents and sometimes by the young people themselves. Sometimes, schools have run workshops, as described in Chapter V, but specifically for parents of school-leavers. Such workshops provide opportunities for parents to support one another both socially, emotionally and at a highly practical level. For example, a suggestion made by a parent who has faced and overcome a particular challenge may be more effective than the same advice given by a teacher on the basis of general principles alone.

Examples of joint work arising from one workshop included a programme to help the mother of a young woman with Down's Syndrome help her daughter to go unaccompanied to visit her next door neighbour when she had previously clutched her tightly in case she ran away. This was followed by suggestions from other parents on sending her unaccompanied to a nearby local shop.

A father initially expressed doubts whether his son was ready to be helped to walk independently to a day centre but worked with the staff in developing a training programme. At first, the father accompanied his son all the way but gradually walked a little behind him and gave him increasing responsibility in deciding which way he had to go and how to cross roads. Finally, his son told him not to follow him or he would be late for his own work!

SPECIAL PROBLEMS OF PARENTS OF ADOLESCENTS

The period of school-leaving marks a critical point in the life of the family as a whole. After several years of full-time schooling, many families are forced to resume full-time care of their relative because of a lack of appropriate services. Sometimes, this means a parent (usually the mother) giving up paid employment in order to remain at home to look after her son or daughter. This in turn is likely to result in a lower standard of living for the family.

Parents of adolescents and young people with disabilities face the same tasks and responsibilities as any other family - namely, to provide a loving and secure home and to prepare them to live independently in the community. But the difficulties they face in this task are considerable. Some arise directly from the nature or severity of the young person's difficulties and the absence of services for this age-group. Others arise from a lack of personal and social support for families. These problems impose additional and in many cases unnecessary handicaps on the young person and on the family.

It is ironic that many families are deprived of services for their son or daughter as well as support for themselves at the very time when they are most in need of it. The needs of families are not only for information, discussion and participation but for opportunities to share their concerns for the future in an open manner. Professionals must therefore have the time and the skills to encourage parents to be open, to listen and respect what they have to say and to be equally open in their turn. Most of all, young people and their families want practical help and resources.

Support of this nature can come from social workers in those countries where the social welfare agencies see the provision of such support as part of their work. It can also come from other parents, meeting together as mutual sources of support or acting as a lobby for the development of appropriate services. Many parent and voluntary organizations around the world have themselves founded sheltered workshops or vocational training services, just as they previously fought to establish schools and nursery classes.

NEEDS OF YOUNG PEOPLE WITH DISABILITIES

The age at which young people leave school varies considerably. In many Western countries children must remain at school by law until they are about 16, in some cases 19 or even 21. In many developing countries, it is only a minority of children who attend any form of secondary education. The majority of children complete the whole of their schooling at around 12 years and are then expected to make a contribution to the life of their community, just like any other adult.

How, then, do we define a young adult? If we are thinking of young people who have left school, we may be discussing a group who are only 12 years old in some countries and 21 years in others. Generalizations about such a heterogeneous group of people and their families are therefore likely to be misleading.

Many young people leaving school may not fully understand why the routine to which they have become accustomed has changed so drastically and why they have to stay at home all day. The result may be boredom and frustration and a tense atmosphere at home. They can easily become resentful at this time because of the lack of opportunities to continue their education and training and find work. Few have access to leisure and recreational activities used by other young people. Many are very isolated and can become passive and institutionalized in their own homes, bound to narrow routines, rarely seeing their friends from school and having few leisure interests which take them outside their homes. They may particularly worry about their lack of opportunity to make new friends and to explore sexual relationships. There are many reports of young people with physical disabilities in particular becoming clinically depressed after leaving school.

One response of young people with disabilities has been to form themselves into mutual support and self-advocacy groups. The growth of organizations such as People First and Disabled Persons International has inevitably led to some degree of conflict with the longer established organizations concerned with disability. These have been mostly run by parents or professionals and disabled people themselves have only recently been asked to join the executive and decision-making boards. Some disabled people prefer to run their own organizations without parents or professionals. Who, then, speaks for people with disabilities? Which body should be received by government and other public bodies?

The concerns expressed by people with disabilities are fundamentally the same as those expressed by parents and professionals. In most countries, there is a strong demand for full participation in the life of the community, access to all local services and equality of opportunity. However, professionals and parents on the one side and people with disabilities on the other may differ about the best way to achieve these objectives and about the most effective way of campaigning for them. For example, people with disabilities are urging their right to paid employment and are not prepared to wait in sheltered workshops or training centres indefinitely. They also resent the low levels of payment and allowances which they receive. Professionals and parents on the other hand, while sympathetic to these aims, often consider them unrealistic in the context both of the disabilities of the individuals concerned and of the economic and employment situation

facing the country as a whole. At this stage, partnerships between parents and professionals must be extended to include the handicapped adults themselves.

WHERE TO LIVE?

The expectation of most families in developed countries is that the time will come when their children will grow up and leave home. Some will live independently near by and visit the family frequently; others will work in another area and perhaps have less frequent contact. Some will leave the family home to get married.

These are not the expectations of most families with a young disabled member. It seems to be taken for granted that families will continue to provide a home for their son or daughter until they become too old or too incapacitated to do so. This too is the expectation of government and other public agencies in most developed countries.

In developed countries, more young people with severe disabilities are being helped to live in ordinary houses, with as much staffing and other forms of support as are needed by the residents. But surveys of parents of young people carried out in several countries suggest that many parents are unaware of developments in the use of supported ordinary housing.

Teachers and social workers might begin at an early stage to encourage parents to discuss their ideas and concerns for the future. Some will insist that they will provide a home indefinitely and that other members of the family have undertaken to continue to do so when they no longer can - particularly brothers and sisters. On further exploration and discussion, parents may express doubts about this. Is it really 'fair' on the brothers and sisters and their spouses? Are they perhaps just wanting to prevent the parents worrying about this matter but would be overburdened and stressed unless other alternatives were also possible?

In many developing countries, however, it is usual for young people to continue to live with or at least very close to their families and in some cases to continue to do so even after marriage. In such circumstances, the family may well expect to provide a home for their disabled son or daughter, though few receive support or assistance of any kind in doing so - e.g. in the form of financial help, respite residential care or the opportunity to discuss problems with social workers or other professionals.

OCCUPATION AND WORK

The majority of people with disabilities are living in poverty in most countries of the world. At a time of world recession and record levels of unemployment, the prospects of employment for people with disabilities seem to be limited. Even in times of fuller employment, however, society's expectations of the employment prospects of people with disabilities have always been low. Consequently, their lives in most countries have been marked by lack of opportunity caused by unnecessarily low expectations. Indeed, it could be argued that society's underestimation of their abilities constitutes their biggest handicap. This is particularly the case for people with intellectual disabilities.

Our concern here is with ways in which parents and professionals can work together to help adults with disabilities to obtain paid work, at least to the same extent as their fellow citizens. In developing countries, survival of the family depends on the availability of some income, however small, from each member of the family. But in many countries, people with disabilities are forced to beg in order to survive. Many end their days in prisons or closed institutions.

But there are some signs of progress. From Peshawar, Pakistan, for example, there are reports of people with disabilities being helped to set up a simple stall in the local market place, selling shawls, prayer mats, matches and numerous small articles. Initially, they are supported by a helper, who may be a relative or a volunteer, who gradually withdraws in order to encourage the individual to undertake transactions with the public.

In developed countries, the role of sheltered workshops, vocational training services and day centres is currently coming under intense critical scrutiny. Although most of these services aim to prepare their clients for employment, the number of people who are placed into open or sheltered employment is very low indeed. Rehabilitation workers and the disabled people with whom they work are themselves dissatisfied with the failure of such traditional methods of training and are now looking for alternatives. In particular, attempts are now being made to place people directly into work and to provide the training required in the work place itself - as in the Peshawar example mentioned above. In addition to training for the job itself, the worker may need social and personal support, learning how to fit in, be on time, find their way around and meet other workers. This essential support is sometimes provided by a relative, volunteer or another worker. It may make all the difference between success and failure in a work placement. Some examples of direct supported work placements are given in Bellamy (1979) and King's Fund (1984).

In developing countries, the Community-Based Rehabilitation Manuals produced by the World Health Organization and the International Labour Office are beginning to be more widely used to develop locally based training for people with disabilities. These are practical training manuals, well illustrated with line drawings and written in simple, clear instructional language which are intended for the use of people without specialist training in the community, including family members. (Copies available through regional offices of WHO or ILO or from the headquarters of these organizations in Geneva. Unesco has also been involved in the development of these materials.)

It is clearly important that families and people with disabilities themselves should be aware of these and similar developments. Unfortunately, information is rarely made available to them and it is left to the initiative of a few individuals to seek out information about new approaches to rehabilitation and service delivery. It would be helpful, for example, if a newsletter were available, issued by government or a voluntary agency, which summarized information about new developments. Such newsletters could provide the basis for discussion between parents, professionals and people with disabilities.

Such newsletters can also do much to promote a positive image of people with disabilities, stressing not only their needs but their achievements. Reference can be made to well-known and respected figures in each country who happen to have a disability, as well as to world statesmen and politicians, famous authors and artists (see 'Think Positive' (Shearer, 1984) for examples of presentation of people with disabilities at local level and in the media).

CONCLUSIONS

The integration of people with disabilities into their local community is beset with many difficulties. Local circumstances vary greatly from community to community, but no one is more directly aware of the obstacles than people with disabilities and their families. If these obstacles are to be overcome, professionals, parents and people with disabilities themselves will between them need to work out new roles, relationships and responsibilities to meet changing and complex needs.

CHAPTER VII: OVERCOMING OBSTACLES

In this final chapter, we draw together a number of examples of good practice and summarize suggestions which have been made for the development of better working relationships between parents and professionals. These examples come from communities at very different stages of development in their services. A number of examples of successful collaboration have come from countries and communities where parents have only the most limited resources and where the development of facilities and staff training are at a very early stage. In contrast, some of the richest countries experience difficulties in moving away from traditional practices which have in the past paid little attention to the importance of working towards better collaboration between parents and professionals.

OBSTACLES TO COLLABORATION

The development of better working relationships is no easy task, and is beset by many obstacles. These have been mentioned by writers from many countries. We will therefore summarize some of the main obstacles to collaboration, and then try to suggest ways in which they might be overcome. We shall see that some obstacles are common to both professionals and parents and that others are more specific to one group than to another.

1. Lack of preparation in training

Few professionals have been adequately prepared by their basic training to learn about the experiences and points of views of parents, nor in general have they been provided with opportunities to discuss ways in which they might work in closer collaboration with parents. Although this is probably less true of recently trained professionals, we doubt whether many training courses have cause to be satisfied with the amount of time devoted to these issues.

It might be argued that students training to be teachers, social workers or doctors are still too inexperienced to take advantage of such information, and that there is no time on a crowded syllabus to air these issues. But failing to provide opportunities to consider and prepare for the development of effective working relationships with families could suggest to students that these are not perceived as important issues for practice.

Given the low priority attached to this subject in either basic or post-experience training, it is not surprising that lack of experience or confidence may make professionals hesitate to take new initiatives in working with parents. Feelings of anxiety and stress in adopting new roles and new relationships are understandable. Alternatively, over-confidence - the 'expert' role that 'the professional knows best' is equally an obstacle to collaboration.

Just as professionals are inexperienced with parents, so the converse is also true. Teachers may not be aware of parental apprehension and even hostility to schools, arising from their own childhood experiences. Although these fears may make for uneasy first encounters, such problems can be overcome once teachers and parents have negotiated and agreed a form of collaboration which suits both parties.

The training of professionals in aspects of collaboration with parents might include the following:

(a) a brief rationale for collaboration;

(b) development of positive attitudes to parents by fostering understanding and empathy of parents' needs and difficulties;

(c) ways in which communication can be facilitated;

(d) range of activities and situations in which collaboration can be developed;

(e) providing situations in which professionals can 'put themselves in the shoes of parents' - e.g. through role play and other simulation techniques.

2. Psychological and social distance

Professionals, by virtue of their specialist training, tend to distance themselves from parents. Because they often perceive themselves to be of higher social and educational status, they may find it difficult to relate to parents as equals, even if the parents come from a similar social background.

The psychological and social distance of professionals from parents tends to result in quite unnecessary secrecy and mystification. Parents have also complained about professionals treating parents as 'patients', their tendency to question the objectivity and accuracy of the information that parents have to convey about their children and their family and their failure to listen to parents' questions and concerns.

Working with parents as partners means that professionals need to learn to adopt a new role vis-a-vis parents. It requires them to shed some of the mystique and distance traditionally associated with the status of professionals. They will need to accept parents as equal partners in the task of working for the child's growth and development. Such changes of role and status can be difficult and painful. For example, it requires professionals to be open in their dealings with parents, to admit when they do not know or when they have made a mistake.

Professionals need to learn how to win the trust and confidence of parents. They need to learn about parents' feelings and their goals for the child, to enlist the experience which the parents already have, to learn and to understand how parents see their own situation.

A working relationship undertaken as a partnership requires not only the skills and techniques which professionals can offer but also an ongoing assessment by parents and professionals together of whether the child's and the family's needs are being met in the way they would wish. This requires consideration of the varying needs of families over time, of their feelings about their own competence and their own social and emotional resources as a family.

Professionals' lack of experience and confidence in working with parents is often matched by feelings of anxiety on the part of parents. They may agree that it would be beneficial for them to work more closely with teachers but may be worried in case they fail to meet what they regard as the teacher's expectations. They may also feel anxious about their own lack of ability and education. It is part of professionals' task to help put parents at their ease and to communicate in language that will be easy to understand.

3. Problems in reconciling the needs of the child with the needs of other members of the family

It is only by getting to know the family as a whole that professionals can learn about ways in which the child is already benefiting from the help being offered by the family. They will also learn about the difficulties which many parents experience in seeking to balance the needs of the child with those of other members of the family. Teachers and psychologists accustomed to planning for the individual child can easily overlook the implications of the child living in a family where there are many other demands to be met. The needs of brothers and sisters, of the mother and father as individuals and as a couple, of other relatives living with or close to the family - all these need to be considered by professionals when planning to involve the family in work with the child.

Sometimes, a social worker plays an important intermediary role in this situation. The training of social workers particularly emphasizes the importance of thinking of the needs of the individual with a disability in the wider context of the family and of the immediate neighbourhood. This is one reason why a social worker is an important member of a multidisciplinary team. In addition, they work with families in order to explore their feelings about their child, their relationships as a family as well as with other professionals and service providers.

4. Unrealistic demands and expectations

If parents and professionals have had only limited opportunities to work together, parents can have too little or too much confidence in the capacity of professionals to make progress with their child. If the child is making only slow progress, it is all too easy to put the blame on the severity of the child's impairments or on the lack of interest or lack of skills of those who are teaching the child. It is only when they begin to work together and realize the possibilities of active joint work and sharing experiences that a more systematic co-ordinated teaching programme can be developed.

On the other hand, some parents are so impressed by the progress made by the child that they may come to overestimate the teacher's skills and therefore underestimate their own potential contribution. This achieves the very opposite result from what is intended. In a true partnership, each person acquires an understanding of both the strengths and limitations of the other. Both parents and professionals are now beginning to understand how much they have to learn from one another and how much the progress of the child depends on their ability to work together in an atmosphere of trust and respect. This can only be created on the basis of a working knowledge of what each side can and cannot be expected to offer. This process requires time and understanding.

Once parents and professionals begin to work together, there is a danger that professionals may make excessive demands on parents. For example, parents may be asked to carry out frequent teaching sessions with their child, to make detailed records of the child's response to every session, to keep a diary recording use of language or the frequency of certain features of behaviour on which parents and teachers are currently working.

Although many parents welcome such detailed collaboration and shared activities, teachers are not always aware of the strains which this may put on a family's resources. They may also not be aware of the feelings of guilt and anxiety which may be aroused if parents find themselves unable to comply with the teacher's demands. Teachers in their turn will need to discuss with each family what

kind of commitment of time would be consistent with the family's needs and resources so that parents do not put excessive demands on themselves.

After all, we know that some families are willing to work for hours at a time with their child if they feel sure that this is going to be of benefit. Some families would not necessarily regard it as a sacrifice of their time to work in this way. A heavy responsibility therefore falls on teachers and others to ensure that the demands that they make are consistent with the resources and needs of the family. This can only be ascertained by professionals asking the family in a sympathetic manner that enables families to share their real views.

5. Under or overestimating the child's abilities

It sometimes happens that parents and teachers take a different view of the child's abilities. But teachers mainly see the child in school, whereas parents have more opportunities to observe the child in a wider variety of natural learning situations; furthermore, it is important that they should provide teachers with examples of the child's response to such situations. Here again, a constant interchange of information and ideas, as well as opportunities for joint assessment, may prevent mutual misunderstanding.

On the other hand, some parents find it difficult to accept teachers' assurances that the child is making progress. They may feel that teachers need to reassure themselves and their superiors of their skills and remain unconvinced that any real development has taken place which can be attributed to teaching. Some parents also find it hard to accept that teachers may have succeeded where they have failed. Here again, such problems are less likely if parents and teachers have worked together from the outset - by undertaking joint assessment, deciding together what the teaching priorities are and, above all in this context, agreeing on ways in which progress can be recorded.

6. Professionals' lack of support from their own management

Although collaboration with parents is increasingly stressed in official policy pronouncements, direct help or support from management and superiors is often not available to staff at local level in actually putting such policies into practice. Greater management support might, for example, result in school staff being given time to visit parents in their homes, or being provided with additional staff to assist with home visits. In addition, it may be possible for a special room to be reserved in the school for parents to meet one another socially and to provide mutual support.

GETTING TOGETHER

In conclusion, we will list a number of ways in which progress can be made in developing better working relationships between parents and professionals. Many of the suggestions have arisen directly from a consideration of the obstacles identified in this chapter, as well as from examples of good practice suggested in the replies to our inquiries. We will merely recapitulate some of the essential elements.

Common to all the suggestions that have been made is the principle that if people are to work together more successfully in the future than in the past, they will have to get to know one another better as human beings first and only secondly in their role of parents or professionals. In other words, it will be necessary to penetrate the barriers erected by society and its institutions, as well as by the individuals themselves.

1. The right and need to know

The most important single need of parents is for information. Often, such information is available but is not easily accessible. Professionals and parents need to work together in order to ensure that all parents can gain access to information about local facilities and resources. Simply produced leaflets and information sheets can be made available, listing people and places where help and information can be found. Health centres, schools, public libraries and other public information centres could collect and display such leaflets and publicity about the availability of relevant information can be disseminated through local civic leaders, religious groups, business organizations and the media. Equally, professionals need to seek information that only family members can give about the child's life at home.

2. Opportunities for making contacts

Parents and professionals can jointly organize a social or 'fun' event of some kind together - a school outing, a display of work, a school open day, a play or musical performance. Differences of role and status are easily forgotten when joint tasks are undertaken. People get to know one another as individuals: in the process, they form likes and dislikes or just remain neutral.

3. Parents contributing to professional training

Although more parents are beginning to contribute to the training of professionals, it is still a comparatively rare event. Parents could talk to groups of students in training - e.g. doctors, nurses and other health professionals, teachers, social workers and administrators. There should always be opportunities for students to discuss issues with parents in small groups and to ask questions.

Parent groups can be asked to suggest parents who would be willing to meet groups of students from time to time and who would be willing to speak not only about their own personal experiences but also on the basis of their knowledge of other parents.

Because initial training courses nearly always have a crowded timetable, in-service training or refresher courses for experienced staff provide additional opportunities for discussion, learning counselling skills through role play and so on. If these are single-discipline courses (e.g. primarily for doctors, teachers, etc.) opportunities can be taken to raise issues specific to the work of these professions. Mixed multidisciplinary courses provide better opportunities for professionals to learn about the experiences of parents, particularly in relation to problems of communication and co-ordination of services.

4. Parents attending professionals' conferences and meetings

Many of the conferences and workshops held for professionals could be thrown open to parents who wish to attend on the same terms as any other participant. This would add an essential dimension to the knowledge available at such meetings.

5. Professionals attending parents' meetings

It is also useful for parents to invite one or more professionals to meet them on their own ground, rather than at a school or clinic. For example, parents may want to have an opportunity to question a teacher, a speech therapist or physiotherapist or psychologist about their work and about developments in their field.

6. Parents as policy-makers

If parents are seen as the consumers, or at least as the representatives of the consumers of the service, it is important that they should be fully represented on local and national policy-making and advisory committees. In some countries, parents have a right to be elected as parent governors of schools, alongside community, teacher and occasionally student representatives.

There are a number of standard professional objections to the presence of parents on such committees. How is a parent selected? Whom do they represent and to whom do they report? Will they only be concerned with the needs of the age-group represented by their relative? Some of the same objections could in fact be levelled against professional members of committees and most are in principle soluble. In fact, parents have a good case to be represented as of right. Furthermore, they can make an effective contribution precisely because they do not represent sectional service interests but

speak for the consumer. However, as we have seen, consumers are increasingly speaking for themselves and demand to be represented on such groups in their own right.

7. Spreading the word

More parents and professionals in many countries and communities are beginning to work together and to learn from one another. But examples of successful partnerships should be more actively disseminated, so that others can be encouraged by their example. Parents and professionals could collaborate in writing articles in newspapers, giving talks on radio and television (both local and national), meeting local groups of citizens, business people, religious leaders, local politicians and civic dignitaries, inviting them jointly to meet the people working in and using the service. In this way, they would learn at first hand about the needs of the service and those who use it and work in it.

WORKING TOGETHER WORKS

Finally, the advice given in a Canadian handbook written for parents provides some useful guidelines on how parents and professionals can improve collaboration (adapted from Brynelsen, 1984):

Parents

do not be afraid to ask for help;

ask to bring a friend or relative with you when you meet professionals;

ask for clarification if information is not clear to you;

challenge professionals if you disagree - be honest about home happenings and explain practical restrictions on time and energy;

seek other kinds of help if you need it (where it exists);

if you are not pleased with professionals' advice or help, tell them;

show your appreciation for good service and attitude.

Professionals

ask for parents' opinions: then show that you value them;

give parents recognition for their strengths and successes;

tell parents they are experts too, through specific and accurate comments;

do not patronize;

believe the parent: children do act differently in different settings;

show respect for children and value them as persons;

accept peoples' right to be different, avoid generalizing and stereotyping;

listen to parents, sometimes they know more than you;

do not press parents to participate.

Partnership between parents and professionals is working in many countries and communities. It is still at an early stage of development and there are many obstacles to be overcome. But there can be no doubt that the resulting benefits to children and young people with disabilities amply repay the effort involved for parents and professionals in working through a sharing of knowledge and skills.

REFERENCES AND FURTHER READING

There is now a considerable literature on collaboration between parents and profess ionals but we have only referred to a small number of publications. The following is a selection of English-language references. An asterisk has been placed against those which provide a useful reference source for other publications.

Anderson, E. and Clarke, L. (1982), Disability in Adolescence. London: Methuen.

Bellamy, G., Horner R. and Inman, D. (1979), Vocational Rehabilitation of Severely Retarded Adults. Baltimore, Md.: University Park Press.

*Brynelsen, D. (ed.) (1984), Working Together: A Handbook for Parents and Professionals. Toronto: National Institute on Mental Retardation and British Columbians for Mentally Handicapped People.

*Cunningham, C.C. and Davis, H. (1985), Working with Parents: Frameworks for Collaboration. Milton Keynes and Philadelphia: Open University Press.

Dessent, T. (ed.) (1984), What is Important about Portage? Windsor: NFER/Nelson.

Featherstone, H. (1981), A Difference in the Family: Living with a Disabled Child. London: Penguin Books.

Hannam, C. (1980), Parents and Mentally Handicapped Children. London: Penguin Books.

Hegarty, S., Pocklongton, K. and Lucas, D. (1981), Meeting Special Educational Needs in Ordinary Schools. Windsor: NFER/Nelson.

Hewett, S. (1970), The Family and the Handicapped Child. London: Allen and Unwin.

Jeffree, D. (1986), The Education of Children and Young People Who are Mentally Handicapped. Paris: Unesco.

Jeffree, D. and Cheselidine, S. (1982), Pathways to Independence: A Checklist of Self-Help Activities. London: Hodder and Stoughton.

King's Fund (1984), An Ordinary Working Life: Vocational Services for People with Mental Handicap. London: King's Fund.

*McConkey, R. (1985), Working with Parents: A Practical Guide for Teachers and Therapists. London: Croom Helm.

Mittler, P., Cheseldine, S. and McConachie, H. (1983), Roles and Needs of Parents of Handicapped Adolescents. In The Handicapped Adolescent: Transition to Work. Paris: CERI, OECD.

*Mittler, P. and McConachie, H. (eds.) (1983), Parents, Professionals and Mentally Handicapped People: Approaches to Partnership. London: Croom Helm.

Mittler, P. and Serpell, R. (1985), Services for People with Intellectual Disabilities: An International Perspective. In Clarke, A., Clarke, A.D.B. and Berg, J. (eds.) Mental Deficiency: the Changing Outlook (4th edition), London: Methuen.

Morton, K. (1978), Identifying the Enemy: A Parent's Complaint. In Turnbull, A. and Turnbull, H. (eds.) Parents Speak Out: Views from the Other Side of the Two-Way Mirror. Columbus, Ohio: Merrill.

Organisation for Economic Co-operation and Development (1981), The Handicapped Adolescent: Integration in School. Paris: CERI, OECD.

*Pugh, G. (1981), Parents as Partners: Intervention Schemes and Group Work with Parents of Handicapped Children. London: National Children's Bureau.

Sandow, S. (1984), The Portage Project Ten Years On. In Dessent, T. (ed.) What is Important about Portage? Windsor: NFER/Nelson.

Schaefer, N. (1978), Does She Know She's There? Don Mills, Ontario: Fitzhenny and Whiteside.

Shearer, A. (1984), Think Positive: Presenting a Positive Image of People with Mental Handicap. Brussels, ILSMH.

*Turnbull, A. and Turnbull, H. (eds.) (1978), Parents Speak Out: Views from the Other Side of the Two-Way Mirror. Columbus, Ohio: Merrill.

Unesco (1979), Report of Expert Meeting on Special Education. Paris: Unesco.

Unesco (1981), Early Detection, Intervention and Education (Argentina, Canada, Denmark, Jamaica, Jordan, Nigeria, Sri Lanka, Thailand, United Kingdom) Paris: Unesco.

Unesco (1985), International Directory of Special Education. Paris: Unesco.

Webster, S. (1975), The Portage Guide to Home Teaching. Windsor: NFER/Nelson.

Whelan, E. and Speake, B. (1979), Learning to Cope. London, Souvenir Press.

*Wolfendale, S. (1983), Parental Participation in Children's Development and Education. London: Gordon and Breach Science Publishers.

World Health Organization (1983), Training Disabled People in the Community: A Manual on Community-Based Rehabilitation for Developing Countries. Geneva: WHO.

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ARGENTINA

Federacion Argentina de Entidades Pro Atencion Al Deficiente Mental (H. Marmorek)

AUSTRIA

Lebenshilfe Oesterreich (Dr W. Eigner, Dr. H. Spudich)

BANGLADESH

Society for the Care and Education of Mentally Retarded Children in Bangladesh (S.R. Akhtar, S.H. Kabir, and Dr H. Adam)

BELGIUM

Association Nationale d'Aide aux Handicapés Mentaux (Dr R. Portray; A. Belpaire, Ghent; J. Lecuyer)

CANADA

National Institute on Mental Retardation (E. Armour, N. Schaefer, D.J. Macoy)

Canadian Association for the Mentally Retarded (Pilot Parents, Toronto)

FEDERAL REPUBLIC OF GERMANY

Lebenshilfe fuer geistig Behinderte (Dr. T. Neuer-Miebach and many publications in German)

FRANCE

Union Nationale des Associations de Parents d'Enfants Inadaptés, Paris (J.M. Brun); Bourg en Bresse (J.J. Bellier); CESAP

HONG KONG

Hong Kong Association for the Mentally Handicapped (M. Lee); Society of Homes for the Handicapped (S.Y. Chan)

IRELAND

National Association for the Mentally Handicapped of Ireland (G. Ryan)

JAPAN

Japanese Association for the Care and Training of the Mentally Retarded (T. Senoo)

MALTA

Ghaqda Ghall-Mentalement Inkapacitati (J.P. Vella)

NETHERLANDS

Bishop Bekkers Institute (Dr S. Nemeth)

NEW ZEALAND

New Zealand Society for the Intellectually Handicapped (J.B. Munro, L. Guerin, G. Hornby)

PAKISTAN

North West Frontier Province Association for the Mentally Handicapped and other societies in northern Pakistan (M. Miles)

Association for Children with Emotional and Learning Problems, Karachi (Z.M. Hasan)

SUDAN

Usratuna for Handicapped Children (A. Bertani)

SWITZERLAND

Federation Suisse des Associations de parents de handicapes mentaux, Bienne

UGANDA

Uganda Association for the Mentally Handicapped (B. Kawooya)

UNITED KINGDOM

Royal Society for Mentally Handicapped Children and Adults (B. Rix, P. Fairbrother), J. Clements

UNITED STATES OF AMERICA

Association of Retarded Citizens, Arlington, Texas (Dr S. Davis)

Three booklets on Parent/Professional Partnerships: (1) The Right to Education; (2) Classroom Programming; (3) The Partnership: How to Make It Work

National Information Center on Handicapped Children and Youth, Washington, D.C. (1985 Directory of Parent Information)

ZIMBABWE

Zimca re Trust (L. Maringa)